Navigating the Cancer Care System

African Nova Scotians' Experience

Patient Navigation Research Project • Final Report – May 2001

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Cancer Care Nova Scotia

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Acknowledgement

Thanks is extended to the African community members who promoted this research initiative within our communities. Thanks is also extended to the African community co-ordinators who were instrumental in ensuring that the voice of rural African community members were heard. Special thanks is extended to all of the participants who gave of their time and openly shared their experiences in order to improve the African Nova Scotian experience within the cancer care system.

Appreciation is also extended to the ***Cancer Care Nova Scotia*** *staff, board members, and the Patient Navigation Working Committee for the input and support that was given to the consultants.*

Introduction:

Cancer Care Nova Scotia is a provincial program of the Nova Scotia Department of Health, created in September, 1998. Partnering with others in the field of cancer and health care, ***Cancer Care Nova Scotia*** co-ordinates, strengthens and evaluates services offered by the cancer system throughout Nova Scotia, to bring about patient centred changes. Directed and advised by a voluntary Board of Directors, ***Cancer Care Nova Scotia*** has instituted a comprehensive and integrated provincial structure through implementing a variety of programs. These programs are community focused, based on sound evidence and aimed at reducing the burden of cancer on individual families, communities and the health care system.

In an effort to assist in the development of the Patient Navigation Program, ***CCNS*** commissioned two African consultants to document the provincial experience of African Nova Scotians as they interact with the health care system. This research study, specific to the African communities of Nova Scotia, will serve to complement an earlier research initiative, Patient Navigation: A Qualitative Study, presented in August, 2000.

Project Goal:

- To develop meaningful actions that can begin to break down the barriers encountered by African Nova Scotian community members, while interacting with the health care system.

Project Objectives:

Cancer Care Nova Scotia wants to improve the way cancer care is provided to members of African communities within the province of Nova Scotia. Delineated below are this project's objectives:

- To facilitate a provincial wide process for African Nova Scotian community members to discuss their experience when they interacted with the cancer care system;

- To document:
  - the provincial experience of African Nova Scotians, while they interacted with the cancer care system; and
  - the meaningful actions/recommendations that can begin to break down the barriers encountered by African Nova Scotian community members, while interacting with the health care system.

Methodology:

An Africentric methodology was employed to achieve the above stated objectives. This approach placed African Nova Scotian people at the centre of the analysis. The primary focus of an Africentric paradigm is to re-assess social phenomena on the basis of an Africentric orientation. Its concern with the liberation of oppressed people is addressed by introducing a world view that speaks to the reality and truth of individual and collective experiences.

Africentric methodology provides an efficient and effective way of understanding and analysing the African Nova Scotian experience. The strength of this methodology is found in the co-operative and integrative function of human experiences. This experience is crucial to ensure that the interpretation of the data relates to the collective African Nova Scotian experience.

Africentric research is holistic, integrative and participatory. The main focus of this project was not to produce a history of African Nova Scotians, but rather to facilitate a discussion among African Nova Scotians, who navigated the cancer care system, about their experiences. This was an opportunity for African Nova Scotian stakeholders (patients, family members and health professionals) to name, describe and analyse their experience, while providing the consultants with recommendations aimed at breaking down the barriers that were encountered while navigating the cancer care system.

Data was collected in a qualitative nature, utilizing various techniques: focus groups surveys, followed-up with a telephone call if necessary and one-on-one telephone or personal interviews. This allowed for flexibility, uniqueness and the uncovering of the deepest meaning of the participants' responses.

Context of this Study:

To gain insight into the application of Africentric research, the consultants will provide a snapshot of African Nova Scotian historical experiences. This snapshot will place African people in the centre of the analysis by highlighting our plight since our arrival in 1606.

Nova Scotia has the largest indigenous African population in Canada and are considered to be among the founding peoples of Nova Scotia. The 1996 Census revealed that 18,105 persons of African descent reside in Nova Scotia. This is the third largest African Canadian population - behind Toronto and Montreal. African Canadians residing in Nova Scotia reside within the forty (40) plus communities. Our arrival to Nova Scotia is resultant of three (3) separate migration intervals. The circumstances upon which we came to Nova Scotia were both voluntary - based on the promise of freedom and land, and involuntary - as a form of social control.

Persons of African descent, living in Nova Scotia, continue to hope for equality and struggle to regain control over our destiny. It was thought that the end of our enslavement would bring about social, as well as legal equality. However, our experience tells us that sociological institutions, including the health care system, are affected by racist ideology and continue to operate from a racist perspective. There is no formal documentation of the status of African Nova Scotians' health and no statistics to suggest morbidity or mortality of disease within the African Nova Scotian Communities. According to many elders, medical care was not available until the late 1930's. Medical services were mainly used for emergencies or pronouncing someone deceased.

Many African Nova Scotians used herbal and natural remedies learned from our African ancestors. Many diseases contracted by early African settlers such as: Tuberculosis, Cancer and Heart Disease, still exist. Our legacy of racial discrimination, dating back to our enslavement, continues to have a psychological impact on our psyche. The direct result of this impacts on individuals not feeling comfortable challenging institutions for services that are considered their right.

Recruitment:

All of the participants who volunteered to participate in this research initiative self-identified as a member from one of our forty (40) plus African Nova Scotian communities and responded to the promotional material (Appendix A) because they met at least one (1) or a combination of the following criteria :

- have been diagnosed with cancer within the past five years;
- have supported an African Nova Scotian friend or family member who has been diagnosed with cancer within the past five years; and
- currently work or have worked in the health profession, within the past five years, and are knowledgeable of the experience of African Nova Scotians who have interacted with the cancer care system.

Notices were developed with a conscious effort to incorporate language that was inclusive and reflective of the research being conducted. Several other recruitment strategies were employed in an attempt to encourage provincial participation and a cross-section of experiences to reflect a collective African experience. These strategies involved:

- Notices were widely distributed via e-mail;
- Support of those who received the e-mail, was solicited to further distribute the notices to other African Nova Scotian community members, in order to ensure that the sample was comprised of all Africans who resided in Nova Scotia and not only those Africans who are indigenous to Nova Scotia;
- Over 700 notices flyers were distributed through African United Baptist Churches;
- Persons living with cancer and/or persons who supported someone who has/had cancer were identified and contacted by African Nova Scotian community member/s and later contacted by one of the consultants;
- Persons living with cancer and/or persons who supported someone who has/had cancer, known to the consultants, were directly contacted;
- African Nova Scotian medical professionals and Pastors were identified and requested to contact individuals known to them, who fit the criteria;
- Notices were shared with and support solicited from members of the African Nova Scotian community who volunteer in the cancer care system to identify/contact individuals who fit the criteria;
- African Nova Scotian community groups were contacted and requested to have either the notice attached to or the information from the notice circulated in their upcoming newsletters;

- African Nova Scotians living outside of the Halifax Regional Municipality, were recruited to identify individuals and/or co-ordinate a focus group/s or individual interviews in their areas on behalf of the consultants;
  community co-ordinators were retained and utilized in a variety of methods, based on the uniqueness of their community/ies to recruit individuals to volunteer their participation in this study:
  - notices were inserted in the church bulletins
  - radio announcements
  - word of mouth
  - notices were sent home with children who participated in cultural programs
  - information from the notice was placed in community newsletters
  - community members known to the community co-ordinator, who fit the criteria, were contacted directly by the community co-ordinator.

Resultant of the above recruitment strategies a total of forty-one (41) participants expressed an interest and volunteered to participate in this research initiative. This number is reflective of:

- Seven (7) health professionals;
- Eight (8) persons who have survived cancer;
- Three (3) persons who are living with cancer; and
- Thirty-one (31) persons who have supported at least one (1) person who had been diagnosed with cancer.

Although a provincial recruitment strategy was employed, participants who agreed to volunteer in this research project resided in the areas delineated below:

- Annapolis County;
- Guysborough County and it surrounding African Communities: Tracadie, Mulgrave, Sunnyville, Lincolnville;
- Halifax Regional Municipality: Halifax, Dartmouth, East Preston, North Preston;
- Yarmouth;
- Shelburne;
- Truro.

Data was collected in one (1) of four (4) following ways:

- Personal interviews (individually or consisting of no more than two (2));
- Telephone interviews;
- Survey with telephone contact, if clarification was required; and
- Focus groups.

Each participant was thanked for their interest in this study and their willingness to discuss this sensitive topic. Participants were advised of the intent of the research and were informed that the information sought was specific to the African Nova Scotian experience. Participants were also advised that the data gathered will compliment an earlier research project that was presented in August, 2000, that all of the information gathered will be kept confidential, and a final copy of this report will be forwarded upon its completion. This information was provided to assist participants with their decision to willingly volunteer.

The consultants were mindful that the findings of the August, 2000 report may be amalgamated with this study in an effort to achieve a comprehensive final document. Therefore, ***Cancer Care Nova Scotia*** was advised that the consultants would use the questions outlined in the Journey maps of Patient Navigation: A Qualitative Study (Appendices B & C of this report) as a guide in the focus groups and interviews to attain the overall goal of this initiative; the development of the Patient Navigation Program.

Key Findings:

This section of the research project will provide the reader with a synopsis of the experiences encountered by African Nova Scotians, as they interacted with the health care system, at various stages of *a diagnoses of cancer.* This data represents a provincial sample, extending as far east as Guysborough and as far west as Yarmouth. Where experiences are specific *only* to rural African Nova Scotian community members, the reader will be advised.

As mentioned in the previous section, data was collected through a variety of methods. Upon analysing the data gathered, given the specific criteria of the population sampled, it became evident that two (2) themes were emerging. Participants identified experiences and issues that were specific to their interaction with the cancer care system, as it related to: the disease; and being of African descent.

The key findings discussed below, will reflect the two (2) themes which emerged, signified by the type of diamond which precedes the experiences/issues raised and will be categorized in relation to the three (3) areas probed:

- Experiences/Issues prior to receiving a diagnosis of cancer;
- Experiences/Issues upon receipt of a diagnosis of cancer; and
- Experiences/Issues after receiving a diagnosis of cancer.

Experiences/Issues Prior to Receiving A Diagnosis of Cancer

Participants discussed the state of the current health care system and the shortages of family physicians; an issue consistently raised in the rural communities. The impact of this shortage is two-fold. It not only infringes upon the individual's right to seek treatment for any ailment and maintain preventative annual check-ups, for the purpose of early detection; but it also impacts on the physician's ability to create a therapeutic relationship with their patients.

❖ Participants gave evidence below to state why they are not happy with their current family physicians. They disclosed that despite their feelings they feel obligated to remain as their patient, due to the above mentioned shortage and the fact that other family physicians, in the area, are not taking new patients. This issue further complicates matters as patients wait longer before they will seek treatment.

- Lengthy waiting periods before you can get an appointment;
- Visit time too short;
- Doctors have business-like attitudes;

- Not confident with the physician's ability;
- Doctors are not culturally sensitive; and
- Feeling of defensiveness as a result of not being respected and listened to.

Participants disclosed that they were confronted with a host of personal experiences resultant of the physician's speculation of cancer. These experiences mainly centred on their emotional response to the potential of the unconceivable outcome.

❖ Levels of stress experienced, while awaiting for test results, were discussed. Participants reported that being tested for cancer was considered to be the last resort and many would convince themselves of a positive diagnoses in order to brace themselves for what might follow.

> ***"This period can be lengthy. Often it takes the physician 2-3 visits to get the whole picture. Then there is a waiting period for an appointment with a specialist, then another waiting period for blood work, X-rays, etc."*** Health Professional

> ***"I remember her saying I might as well accept the fact now - I know what he's going to tell me - it will make it easier to accept when I'm told later."*** Family Member

> ***"Most times it takes several weeks ... this is a very stressful time and would be beneficial if the time could be shortened...patients usually anticipate the worst."*** Health Professional

❖ Information received at this stage: oral and written was reported to be sufficient. Those who wanted more either sought additional written materials: brochures or surfed the Internet or inquired with community persons. Others stated that during this stage, their emotional well being was challenged and their concerns reflected how they would cope, if the tests were positive, and their quality of life.

> ***"Patients need to read info over several times to absorb the possibility that they could have cancer."*** Health Professional

Experiences/Issues Upon Receipt of a Diagnosis of Cancer

Nova Scotia has a high rate of cancer; and within Nova Scotia the African Nova Scotian community has a higher mortality rate. Resultant of this, participants reported that ***cancer*** is interpreted to be synonymous with ***death***, despite the increase in research and preventative interventions.

Participants reported that this way of thinking contributed to the array of emotions they experienced during this stage - anxiety, confusion, denial, fear, justification and vulnerability.

Determinant such as the patient's: 1) relationship with his/her doctor, 2) knowledge of and accessibility to resources, and 3) support system can enrich patients' and their family members' journey through the cancer system, during this stage.

- Patients and family members advised that test results were conveyed by the patient's family/attending physician. In several cases, patients were accompanied by a family member or a close friend.

  "I feel the attending physician should advise the patient of their diagnoses, as the physician can answer any questions arising." Health Professional

  "Patients often ask what are the chances of survival. The physician should answer this question. It is the doctor's responsibility to inform the patient of their diagnoses." Health Professional

  "I think it is appropriate for the physician to give patients the diagnoses because the patient may have additional questions, such as treatment options, prognoses, etc." Health Professional

- A cross-section of participants reported that the patient's relationship with his/her family/attending physician is of eminent importance. Those participants who reported a longstanding open relationship with their physician, spoke of the empathetic, supportive and encouraging roles they played. This level of comfort provided opportunities to discuss their concerns and fears relating to cancer, which empowered patients to take control of their illness. This level of comfort may not be the case when an individual is referred to a specialist.

  "I feel respected in my relationship with my doctor and I am comfortable to ask her anything. I had been going to her for a long time." Patient

  "...someone with whom the patient feels comfortable and can offer [the patient] support during this time of the diagnoses." Health Professional

- One participant in particular discussed the varied ethnic composition and the skill level of the team who diagnosed and treated her mother. She reported that both she and her mother felt confident in the team's decision and ability.

  "The team was very experienced in the particular type of cancer that my mother was diagnosed with. Members were well travelled and continuously conducting research in this area". Family Member

- Participants reported that their family/attending physicians presented "detached" from the process when the diagnoses was revealed. This behaviour was witnessed by family members during their attempts to seek information from the physician, specific to the illness. Other participants commented that it appears that physicians experience great difficulty when discussing cancer diagnoses.

  "The doctor could not tell him that he was dying." Family Member

  "Emphasis should be put on educating professionals to deal with the 'human' aspect." Health Professional

  "Professionals need to deal with the 'human component' rather than the medical component." Health Professional

- Patients reported that nothing could have reduced the overwhelming feelings they experienced, as a result of receiving a positive cancer diagnoses. They spoke of feeling "numb" which affected their ability to retain critical information that was given to them by their family/attending physician. This not only challenged their ability to effectively process the information they received and their coping style/s, but it also began the reality of a journey that they hoped they would never have to travel. Some patients reported that they had someone attend their appointments with them.

  "This is a very stressful time. Despite having procedures explained, the fear of the unknown causes a great deal of worry." Health Professional

  "Once he told me that I had cancer, it was very difficult for me to focus or to hear what the next steps were." *Patient*

  "The shock of the diagnoses is too great. They need to have someone to talk to when they are ready." Health Professional

"After he said cancer, I didn't hear another word he said." Patient

"I always take my mother with me to make sure I hear everything that is said." Patient

- Participants shared the lifestyles of individuals who were diagnosed with cancer: good eating habits and/or engaged in preventative medical practices; and/or sought and received treatment, for a significant period of time as a result of reporting specific symptoms. This discussion questioned the research that provided profiles of the individuals diagnosed with cancer and the doctor's ability to interpret all patients' symptoms. It also questioned whether or not the medical profession recognized the importance of researching cancers that are specific to the African Nova Scotian (Canadian) population.

  "Cancer was the last thing we thought. She took such good care of herself, better than I and lots of other people did." Family Member

  "It's scary to think that even when you take care of yourself you can still get cancer. This left a lot of people questioning if there are any benefits of taking care of yourself." Family Member

  "Our people die from types of cancer that are curable." Health Professional

- Participants reported incidents where individuals consistently described symptoms that were characteristic of the type of cancer they were diagnosed with. After the physician was not successful to eliminate the symptom, previously reported, it was the persistence by the patient that resulted in testing or an appointment to see a surgeon or an oncologist; however scheduling was not done with a sense of urgency. Once the individual was diagnosed with cancer, it was felt that family physicians took no responsibility for, or offered an explanation in relation to the lateness of the diagnoses. Participants questioned the level of training some doctors received in the area of cancer. This area of discussion still remains traumatic for several family members who were involved.

Appointments to see specialists are not readily available, due to the shortages and their schedules. These circumstances also made it difficult to seek alternate opinions, if this is the wish of the patient or members of his/her family. The above areas evoked anger as participants talked about the number of meaningless deaths and malpractice cases against African Nova Scotian community members.

"Blacks are referred to specialists too late." Health Professionals

"My brother was treated with muscle relaxers, even when there was suspicion from his doctor. Cancer was ruled out because he did not fit the profile of the white men who are normally diagnosed with this type of cancer. Family Member

"An Elderly woman from my community wasn't officially diagnosed until the week prior to her death. Very traumatic for family members and negligent on health care providers involved." Health Professional

- Family members reported that their emotions affected their ability to provide initial support. They reported that they required time to process their own emotions associated with their family member's illness, in order to remain strong and provide them with the needed support.

  "I felt helpless. What could I possibly say? I became consumed with the possibility of losing my sister and in hindsight, started a grieving process before she was gone." Family Member

- Participants raised the need for various types of information. Among patients, opinions differed in that some only wanted to hear what they wanted to know, while others wanted everything shared with them. Family members reported that they felt it was necessary to know as much as possible about the disease, treatment, community, cultural, spiritual and health care based resources, in addition to information that would support them in being a support. Questions posed by participants and the discussions which ensued suggest that the participants' level of awareness, pertaining to the determinants of cancer, still remains at a basic level.

  "I wanted information that was going to tell me why me." Patient

  "As a support I needed to know everything, if not more than my sister, to help her feel comfortable about the decisions she made." Family Member

  "Patients need to know that they have a right to ask as many questions about their disease that is needed to better understand the process, treatment options, prognosis." Health Professional

> ***"How do you get cancer? Is it in the water? Can you get it from using microwaves? In what way/s does smoking contribute to cancer?"*** Family Members
>
> ***"What resources are available in the Black community?"*** Health Professional

Those that have had access to resources reported that they have sought out additional information on their own. This supported participants comments that information must be diversified, readily available and delivered in and accessible by a variety of mediums to address the individual's personal, cultural, social, psychological and spiritual needs.

- Several participants reported that detailed information, pertaining to the type of cancer diagnosed was not available, as the research sample spoke to the experience of the non-African community. This was troublesome for both patients and their family members who did not feel confident that the treatment prescribed would eliminate the cancer cells.

> ***"Information for African Nova Scotians is practically non-existent. We have to rely on information received from the US, including research."*** Health Professional
>
> ***"My sister was told that the type of Cancer she was diagnosed with is rare to African people and they did not have any details as to how it would effect her."*** Family Member
>
> ***"As a Black woman, the books and literature I have read on U. S. data has been most useful."*** Health Professional

Experiences/Issues after receiving a diagnosis of cancer.

After being diagnosed with cancer, patients have the right to participate in or refuse a treatment plan designed specifically to combat the type of cancer, related to the stage of its prognosis. This point of the journey dictates different participant needs, from those listed above.

- The information that is communicated to patients, their family members and among varied levels within the health profession is essential to this stage of the diagnoses. Frequent communication among all levels of health professionals who are involved in the treatment, and effective transmission of the patient's treatment plan/option, in lay terms to patients and their family member/s, is crucial to ensure everyone is receiving the same message.

> ***"Because oncologists are so busy, information may not be communicated to family physicians unless requested."*** Health Professional
>
> ***"Communication contents depends on age of patient - doctors usually discuss disease more than person."*** Health Professional
>
> ***"Communication lines must be open between all involved so patients receive same messages from everyone."*** Health Professional

- Health professionals shared their wealth of knowledge as a result of direct and indirect nursing practices associated with cancer patients and their families. Also, many of the participants from this sample acknowledged that their experiences extend to their personal life, as several provided care for their family or community members. In addition to their nursing functions, they reported that they become a support to patients and their families and an advisor to the attending physician.

  Nurses talked about the varied contacts they made on behalf of patients and family members and assisting doctors to understand African traditions and values. Various participants commented on family physicians being insensitive and making inappropriate remarks associated with the diagnosis. Mention was also made in respect to the racist attitudes of non-African nurses.

  > ***"We need more African health professionals on the cancer health team, perhaps this would make African patients feel that they have a voice, or network through which their concerns may be expressed, heard, listened to and acted upon."*** Health Professional
  >
  > ***"We also have to explain the background from which the patient comes to accommodate understanding."*** Health Professional
  >
  > ***" One consistent message from mainstream health professionals is not in so many words we need to be led, assisted and taught by mainstream organizations. Often I have heard Black clients complain about poor treatment, patronizing attitudes by mainstream health professionals..."*** Health Professional

- Health professionals advised that it is important to "act as a sounding board" and to facilitate a discussion that explores the patient's perceptions, fears and beliefs about cancer. Also, it is important to explore the patient's support system, provide patients and their family support through: informing them of community resources, advising family members of self-care programs and ensuring that appropriate reading materials are made available.

  "You inform patients that there are many types of cancer and there are many treatment methods, and inform the patient that their oncologist will design a treatment program tailor-made to their type of cancer. The patient can be told of various diagnostic tools and their effectiveness in diagnosing." Health Professional

- Participants gave evidence of situations where pertinent information, specific to the progression of the illness was withheld. Primary caregivers expressed their concern as they felt that this information was critical in helping them to care for their family members.

  " After my sister was admitted to the emergency as a result of taking a seizure, her specialist stated "I didn't know it was going to spread to her head that fast." Family Member

- Participants advised of specific racist acts they experienced during this stage of their journey:

  "Prior to taking my mother for treatment, her physician advised that I could get support to transport her back home, when her treatment was finished. This was defined as a basic service that an organization in the cancer care system provided. Upon securing this service, I was questioned as to my citizenship, because only Canadian citizens could utilize this service. This experience still angers me today, because ever since I arrived in Canada I donated faithfully to this organization. Never once did they question my citizenship as they took my donations. Would they have questioned my citizenship if I was White and did not speak with an accent? All this over approximately fifteen dollars." Family Member

> ***"My mother was treated differently when she was in the hospital and I know it was because of her race and that her English was not fluent. This made non-African nurses apprehensive of entering into a dialogue with her, which resulted in her basic needs not being met: rubbing her back and ensuring she was comfortable and able to eat Western foods. It was upsetting to see the attention they afford White patients."*** Family Member

- Participants, residing in the rural communities, questioned why they were not made aware of the range of services that became known as a result of non-African patients utilizing these services: ranging from respite/support for the primary care giver to transportation to Halifax for treatment.

> ***"How do White people become aware of these services?"*** Family Member
>
> ***"I spent $300 on a cab to Halifax to take my mother up for her treatment."*** Family Member
>
> ***"No one talked to me about home care... I am so tired that I am beginning to resent caring for him, and I do not like feeling this way. This is not how I want to spend the last days with him."*** Family Member

Conclusion:

Nova Scotia has a high rate of cancer and a higher mortality rate among African Nova Scotians. Why is this?

Qualitative data gathered to document the African Nova Scotian's experience while interacting with the cancer care system, revealed that the emotions that were experienced associated with:

- being tested due to the suspicion of having cancer,
- being diagnosed with cancer, and
- undergoing cancer treatment,

were compounded as a result of being of African descent. This was evident in the two (2) themes which emerged upon analysing the data received from participants:

- interaction with the cancer care system, as it related to the disease; and
- interaction with the cancer care system, as it related to being of African descent.

Determinants such as the patient's: relationship with his/her doctor, accessibility to resources and information, supports systems, level of interaction with the health care system and the communication among health professionals can enrich the patients' and their family members' journey through the cancer care system.

Our legacy of racial discrimination, dating back to our enslavement, continues in current social institutions, including the health care system, and psychologically impacts upon our psyche. Today, persons of African descent, living in Nova Scotia continue to hope for equality and the participants of this research project hope that their recommendations, listed below, will assist African Nova Scotians in regaining control over our health.

Recommendations:

There Is a Need for More Culturally Specific Materials:

Many people expressed the fact that mainstream society have better access to printed materials, therefore are better informed in preventative care. This information is not available/accessible to African community members who are placed at a higher risk.

Cancer Specialists Need to Be More Sensitive:

African Nova Scotians indicated that members of their families and friends experienced specialists with little or no sensitively to their cultural background. This factor makes people leery of diagnosis and process.

Community Recruitment for Health Professionals:

If has been noted that there are few African professionals in the health care system which makes African Nova Scotians uncomfortable with their care. They feel there is no one to relate to, regarding their experience.

Properly Trained Volunteers Re: Anti-racism Education:

Patients and care givers found that volunteers within the health care system need to be more aware of racism and its effects on the African Nova Scotian community, this education process is critical to begin to heighten their awareness.

Research Specific to African People:

It was expressed by those researched that the only research available to African people is based on United States statistics. Specific research based on our African Nova Scotian experience is required.

Formal Recognition Given to Supportive Services Already Available in the African Nova Scotian Community:

Information was shared by those researched that there are supportive services presently available in the African community and that the health care system must recognize and respect these community based resources.

Need for African Outreach Workers; from the Same Community or Area:

Rural community members expressed an interest in continued health awareness and found this process to be therapeutic. It was expressed by both patient and care givers that outreach workers need to be hired and these individuals should be from and aware of the concerns in their perspective area.

Multi-Disciplinary Approach Needs to be in a Calm Non-Hurried Atmosphere and More Sensitive to the Individuals Involved:

Patients and care givers expressed concerns that they received mixed messages when information was shared with them by their family/attending physician. This information was presented in a hurried manner and lacked sensitivity towards individual's feelings.

Emotional/Financial Assistance Provided from Diagnosis Through the Various Stages:

Many patients and family members shared that there was little or no emotional support provided by the health care system and that they felt 'isolated' during their illness which made their experience more dreadful. Many of the drugs needed to assist with their care were not covered through MSI. Also, the amount of travel required by those living in rural areas made it difficult to maintain financially.

24-Hour Hot Line That Patients/Family Members can Access and be Supported by a Health Professional:

Patients and care givers felt that there were a lot of questions and concerns they were not comfortable expressing themselves with doctors or surfaced after the doctors office was closed. A hotline would provide individuals with a response to the information they required, 24 hours a day.

Home Care Is Presently Inadequate, Therefore Training for Family Members Could Assist Them with the Patient Care:

Since it was expressed during our research that home care could not meet all the needs of many of the patients with cancer, it was felt that if family members could be properly trained to provide the additional care that home care is not able to provide.

Appendix A

Cancer Care Nova Scotia
1278 Tower Road, Bethune Building 574
Halifax, Nova Scotia, Canada B3H 2Y9

***Cancer Care Nova Scotia* wants to improve the way cancer care is provided to members of African/Black communities within the province of Nova Scotia.**

Therefore..... If you are of African/Black ancestry and.....

√ have been diagnosed with cancer within the past five years,

OR

√ have provided support and/or care to a family member or a close friend, who has been diagnosed with cancer within the past five years,

...**you** are invited to participate in a African/Black community discussion (focus) group about your journey through the cancer system. Focus groups will be held in several African/Black communities throughout the province over the next few months.

Please contact either researcher: ***Sandra Loppie at 454-3600 or Winnie Benton at 876-1185*** **(wbenton@hfx.eastlink.ca)** to gain further information or to confirm your interest. Come and share your stories (good or bad) and/or your ideas to improve the journey/experience for African/Black Nova Scotians. All information gathered will be kept confidential.

Discussion groups are scheduled to begin in January, 2001. Travel and childcare expenses will be reimbursed.

Appendix B

Journey Map Discussion (care giver)

Pre-Diagnosis: What sorts of feelings and thoughts did you have at the time? How did you feel about the amount and the kind of information you received? Was it enough, too much, not what you need? Where did you get the information? Was there information available? What sort or kind of information did you want? How long was it from the time you knew there was something wrong until your family member was diagnosed?

Diagnosis: How was your family told? Were you with them? In what manner did you find out? How did you feel? Was there anything or anyone that could have made receiving this information any easier and if yes, who and why? What about the information? Did you receive any? If yes, what kind of information did you receive and from who? What did you think about this information? Was it useful? Was it adequate? Did you want any information? How long was the time from diagnosis until your family member or friend was referred to a specialist/started treatment?

Treatment: How did you feel? What were your thoughts? How did your family member/friend decide what treatment option he/she would choose? What did you do? Did you feel you and your family member/friend were adequately prepared for treatment? Why or why not? What information, if any, did you want to receive and why? Did you go looking for information on your own? If yes, where did you go and why? What or who was your primary support and why?

Adapted from Patient Navigation: A Qualitative Study, August 2000. Prepared for ***Cancer Care Nova Scotia*** *by Corporate Research Associates Inc.*

Appendix C

Journey May Discussion (participants)

Pre-Diagnosis: What sorts of feelings and thoughts did you have at the time? How did you feel about the amount and the kind of information you received? Was it enough, too much, not what you need? Where did you get the information? Was there information available? What sort or kind of information did you want? How long was it from the time you knew there was something wrong until you were diagnosed?

Diagnosis: How were you told? In what manner were you told? Was anyone with you? How did you feel? Was there anything or anyone that could have made receiving this information any easier and if yes, who and why? What information? Did you receive any? If yes, what kind of information did you receive and from who? What did you think about this information? Was it useful? Was it adequate? Did you want any information? How long was the time from diagnosis until you were referred to a specialist/started treatment? How many health professionals did you see? How did you feel about the number/kind/type of health professionals that you saw? Why do you feel this way?

Treatment: How did you feel? What were your thoughts? What did you do? How did you decide on your treatment option? Did you feel you were adequately prepared for treatment? Why or why not? What information, if any, did you want to receive and why? Did you go looking for information on your own? If yes, where did you go and why?

Adapted from Patient Navigation: A Qualitative Study, August 2000. Prepared for ***Cancer Care Nova Scotia*** *by Corporate Research Associates Inc.*